

# National Program of Cancer Registries (NPCR) Program Standards 2022–2027

## Acronyms

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AMP	Award Management Platform
APR	Annual progress report
BRFSS	Behavioral Risk Factor Surveillance System
CCR	Central cancer registry
CHSDA	Contract Health Service Delivery Area
CRCCP	Colorectal Cancer Control Program
CTR	Certified tumor registrar
DER	Data evaluation report
DMP	Data management plan
DQE	Data quality evaluation
EHR	Electronic health records
ETC	Education and training coordinator
FHIR	Fast healthcare interoperability resources
FTE	Full-time equivalent
FTP	File transfer protocol
HL7	Health Level Seven
HPV	Human papillomavirus
IHS	Indian Health Service
IT	Information technology
MOU	Memorandum of understanding
NAACCR	North American Association of Central Cancer Registries
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCCCP	National Comprehensive Cancer Control Program
NDI	National Death Index
NOFO	Notice of funding opportunity
NPCR	National Program of Cancer Registries
NPCR-CSS	National Program of Cancer Registries Cancer Surveillance System
OM	Operations manager
PD	Program director
PEI	Program evaluation instrument
PI	Principal investigator
QA	Quality assurance
QC	Quality control
SDOH	Social determinants of health
SEER	Surveillance, Epidemiology, and End Results
SES	Socioeconomic status
TA	Technical assistance
USCS	United States Cancer Statistics

# Introduction

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The goal of CDC's National Program of Cancer Registries (NPCR) is to collect, report, and disseminate high-quality data on all reportable incident cancer cases in a timely manner for the purpose of cancer prevention and control. The NPCR Program Standards are a set of interrelated expectations and requirements that provide a framework for effective cancer surveillance program implementation, evaluation, and continuous improvement. They build on one another to equip central cancer registries (CCRs) to assess the cancer burden through the collection, use, and dissemination of complete, timely, and high-quality cancer data. They are based on the 10 Essential Public Health Services ([www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html](http://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html)) that seek to protect and promote the health of all people in all communities, and are aligned with the Healthy People 2030 cancer objectives.

The NPCR Program Standards also ensure that CCRs fulfill the overarching performance measures listed below, establish priorities and perform activities that funded programs are expected to achieve, provide objective measures of program progress, and improve program processes that drive outcomes.

The 2022–2027 NPCR Program Standards build on progress achieved during the previous notice of funding opportunity (NOFO DP17-1701) to support and strengthen population-based CCRs and promote ongoing registry data use to inform evidence-based decision making.

At a minimum, an NPCR-funded CCR must be able to:

- Report cancer incidence trends by geographic area and provide cancer data to support cancer control programs.
- Collect and report incidence, burden, and stage data and use these data to create surveillance reports that can direct targeted interventions, guide research, and evaluate the success of cancer prevention and screening programs.
- Identify disparities by age, gender, race, ethnicity, and geographic areas in cancer incidence, stage at diagnosis, and mortality.
- Create and maintain registry and state or territorial policies that support use of cancer registry data for research.
- Strengthen its capacity to receive electronic reporting from facilities, labs, physician practices, and other data sources.

We organized CDC's 2022–2027 NPCR Program Standards by strategy, standards, corresponding activities, and performance measures. These standards are based on the legal authority provided to CDC under the Public Health Service Act (Title 42, Chapter 6A, Sub-Chapter II, Part M, § 280e) and subsequent amendments, and apply to all reportable cancers as defined in the Act and amendments. The relevant outcomes, as depicted in the NPCR logic model, and performance measures, which quantify progress toward performing activities and achieving outputs, are also included. Program standards may be revised during the 5-year cooperative agreement performance period.

## Short-, Intermediate-, and Long-Term Outcomes

The following outcomes are the intended results of activities in the NOFO that awardees are expected to achieve by the end of the 5-year performance period.

### *Short-Term Outcomes*

- Increased use of NPCR data by recipients, partners, collaborators, and researchers.
- Achievement of data quality standards by the CCR.
- Successful adoption of data modernization strategies.
- Improved timeliness, quality, completeness, and confidentiality of NPCR surveillance data.
- Increased collaboration among chronic disease and other public health programs.
- Increased access to cancer screening and preventive services among populations of focus.
- Increased knowledge about cancer prevention, screening, and survivorship among populations of focus.
- Increased reporting of high-quality program data to CDC.
- Increased use of evaluation findings for program improvement.
- Increased participation in special studies.

### ***Intermediate-Term Outcomes***

- Increased capacity, flexibility, and utility of CCR infrastructure to meet new data needs.
- Increased data use for cancer prevention and control.
- Improved health behaviors.
- More cancer primary prevention resources and screening available for populations of focus.
- Increased early detection of cancer among populations of focus.

### ***Long-Term Outcomes***

- Reduced cancer risk factors such as tobacco use, overexposure to ultraviolet rays, human papillomavirus (HPV) infections, and overweight and obesity.
- Better quality of life among cancer survivors.
- Decreased cancer incidence, morbidity, and mortality.
- Reduced cancer disparities.
- Increased health equity.

NPCR will monitor and assess the CCR's progress, results, and overall impact through:

- The annual National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) data submissions that monitor data timeliness, quality, and completeness.
- Regular assessments including recipient quarterly check-in responses, the Program Evaluation Instrument (PEI), and the Data Quality Evaluation (DQE).
- Annual Progress Reports (APRs).
- Regular communications with program consultants, such as conference calls and requests for technical assistance.

### **NPCR Logic Model Outputs**

The NPCR logic model outputs correspond to multiple program standards. Since NPCR strategies and outcomes are interconnected, the NPCR Program Standards serve as building blocks that guide cancer registry program implementation and ongoing program improvement.

- Infrastructure in place for data collection.
- Reduced staff attrition; critical registry positions filled.
- Ongoing trainings and educational sessions for registry staff and facility registrars conducted.
- Cancer data processed and collected.
- Quality control procedures implemented.
- Completeness and data quality compliance reports completed.
- Data confidentiality and security maintained.
- Disaster plan that includes risk assessments, data breach plan, and security audits created and updated.
- CCR Operations Manual reviewed and updated.
- Required and additional data linkage performed.
- Effective and sustainable multi-sectoral collaborations developed and strengthened.
- Data modernization projects implemented.
- De-identified cancer data submitted.
- Cancer and related data shared with diverse partners and collaborators.

# Strategy 1: Enhance NPCR data quality, completeness, use, and dissemination

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## **Standard 1.1: Legislative Authority**

**Ensure that legislation supports cancer surveillance and has flexibility to meet innovations in the field.**

### ***Activities***

**1.1.1:** Maintain existing law or regulations that provide legal authority for a CCR, as defined in Public Health Services Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing NPCR.

**1.1.2:** Update existing law or regulations as needed to support criteria specified in Public Health Services Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e specifically addressing and complying with electronic reporting, data exchange, data modernization and innovation, and data sharing and use requirements.

### ***Performance Measure***

**PM 1:** CCR reviews state or territorial cancer registry legislation **at least once per year**, works with state or territorial public health and policy entities to recommend revisions as needed, and provides an update in the Annual Progress Report (APR) narrative.

## **Standard 1.2: Administration and Operations**

**Maintain effective and efficient processes and high-quality staff to operate the registry.**

### ***Activities***

**1.2.1:** Hire or retain staff sufficient in number and expertise to manage, implement, and evaluate the CCR, as well as use and disseminate the data. Core required staff must fill the following roles: program director, project director, or principal investigator (PD/PI) or operations or registry manager (OM), quality assurance or quality control (QA/QC) manager, information technology (IT) staff, and education and training coordinator (ETC). The QA/QC manager and ETC positions must be filled by qualified, experienced certified tumor registrars (CTRs).

• PD/PI or OM	1 full-time equivalent (FTE)	100%
• ETC	1 FTE	100%
• QA/QC manager	1 FTE	100%
• IT staff	0.25 FTE	25%

**1.2.2:** Ensure policy and procedure manuals are up-to-date and staff are cross-trained in key functional areas to maintain continuity of operations. At a minimum, the CCR Operations Manual contains:

1. The reporting laws and regulations.
2. A list of reportable diagnoses.
3. A list of required data items.
4. Procedures for data processing operations, including:
  - Monitoring timeliness of reporting.
  - Receipt of data.
  - Database management, including a description of the registry operating system software (this may be accomplished by citing a software vendor's website and documentation).
  - Conducting death certificate clearance.
  - Implementing and maintaining the quality assurance or quality control program, including procedures for:
    - Conducting follow-back to reporting facilities on quality issues, including rules for identifying when action or further investigation is needed.
    - Conducting record consolidation.
    - Maintaining detailed documentation of all quality assurance operations.
    - Education and training.
  - Conducting data exchange, including a list of states and territories with which case-sharing agreements are in place.
  - Conducting data linkages.
  - Ensuring confidentiality and data security, including disaster planning.
  - Data release, including access to and disclosure of information.

- Maintaining and updating the operations manual.

5. Management reports that include processes and activities to monitor the registry operations and database.
6. An abstracting and coding manual that is used by reporting sources that abstract and report cancer cases.

**1.2.3:** Ensure that adequate hardware and software systems are in place to support the CCR activities, including data collection, database management, interstate data exchange, data linkages, quality assurance, data analysis, and management reporting. Provide the memorandum of understanding with the IT department if IT staff are not embedded in program.

**1.2.4:** Develop or use promising practices and tools to strengthen communication with data reporters to improve data quality, completeness, and timeliness.

**1.2.5:** Implement promising processes to improve real-time reporting and data quality.

**1.2.6:** Ensure the confidentiality and security of CCR data through software and hardware security standards. This includes:

1. Implementing and documenting security policies and procedures.
2. Documenting data release policies and procedures that include both access to and disclosure of information.
3. Developing a disaster plan that includes annual risk assessments, security audits for registry data, and a mechanism to track ongoing security training for staff and telework options. Details are included on the NPCR data security pages at [www.cdc.gov/cancer/npcr/tools/security/](http://www.cdc.gov/cancer/npcr/tools/security/).
4. Developing, submitting, and implementing a data management plan (DMP) that conforms with CDC requirements and guidelines.

### ***Performance Measures***

**PM 2:** CCR secures necessary registry management and operations staff per NPCR Manual and NOFO requirements (core required positions: PD/PI or OM, 1 FTE 100%; ETC, 1 FTE 100%; QA/QC manager, 1 FTE 100%; and IT staff, 0.25 FTE 25%).

- **Target:** At least 75% of required CCR staff positions are filled on an annual basis.

**PM 3:** CCR reviews Operations Manual **twice per year**, updates sections as needed, and provides an update in the APR narrative.

**PM 4:** CCR reviews data management plan (DMP) **once per year** and updates as needed.

**PM 5:** CCR maintains a list of reporting facilities that is verified and updated **once per year**.

### **Standard 1.3: Data Collection, Content, and Format**

**Ensure that the registry collects all reportable data in accordance with NPCR requirements.**

#### ***Activities***

**1.3.1:** Central cancer registries must collect and submit data for all reportable cancers and benign neoplasms including, at a minimum, primary site, histology, behavior, date of diagnosis, race, ethnicity, age at diagnosis, sex, stage at diagnosis, and first course of treatment, according to CDC specifications and other information required by CDC.

**1.3.2:** For all CDC-required reportable cases, the CCR collects or derives all required data items using standard codes prescribed by CDC.

**1.3.3:** Regardless of residency, the CCR collects data on patients who were diagnosed or received the first course of treatment in the registry's state or territory.

**1.3.4:** The CCR uses a standardized, CDC-recommended data exchange format to transmit data to other central cancer registries and CDC.

## ***Performance Measures***

**PM 6:** CCR conducts bi-weekly or monthly check-ins with reporting facilities to ensure timely reporting of cancer cases.

**PM 7:** CCR creates a remediation plan to address reporting challenges due to staff turnover, software issues, or other reasons for reporting delays within 60 days and shares its expectations with the reporting facility.

## **Standard 1.4: Electronic Data Exchange**

**Use and promote electronic reporting among facilities and data sources.**

### ***Activities***

**1.4.1:** Develop and implement a plan to enhance timely reporting via the expansion of electronic reporting by one or more means such as data modernization activities, electronic health record (EHR) reporting, and ePath reporting, and through data exchanges including interstate data exchange.

- The CCR is required to adopt and use standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data (see CDC NPCR Electronic Reporting and Data Exchange Guidance). Registries should promote the use of these formats by reporting sources that transmit data to the registry electronically. CDC-recommended data exchange formats include:
  1. Hospital reporting: The North American Association of Central Cancer Registries (NAACCR) record layout version specified in year-appropriate *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*.
  2. Anatomic pathology laboratory reports: NAACCR's *Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* version 5.0 (or newer standards such as HL7 FHIR).
  3. Non-hospital sources using electronic medical records: Office of the National Coordinator for Health Information Technology (ONC) Certification Criteria 2015 Edition: Health Level Seven (HL7) Clinical Document Architecture (CDA<sup>®</sup>) Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, Draft Standard for Trial Use (DSTU) Release 1.1- US Realm, or newer standards such as HL7 Fast Healthcare Interoperability Resources (FHIR).
- For hospitals reporting to the CCR, increase the percentage reporting electronically every year to meet the standard of all hospitals reporting electronically by the end of the 5-year performance period.
- For non-hospital facilities reporting to the CCR, increase the percentage reporting electronically every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the 5-year performance period.
- The CCR uses a secure Internet-based, file transfer protocol (FTP), https, or encrypted e-mail mechanism to receive electronic data from reporting sources.

## ***Performance Measures***

**PM 8:** Percentage of labs reporting data electronically using HL7 2.5.1 or other standard HL7 format (measure for e-path reporting).

- **Target:** Increase the percentage of labs reporting data electronically in the designated HL7 format by 3% each year.

**PM 9:** Percentage of hospitals reporting electronically to the CCR each year.

- **Target:** Increase the percentage every year to meet the standard of 100% of hospitals reporting electronically by the end of the 5-year performance period.

**PM 10:** Percentage of non-hospital facilities reporting electronically to the CCR each year.

- **Target:** Increase the percentage every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the 5-year performance period.

## **Standard 1.5: Data Completeness, Timeliness, and Quality**

### **Cancer data meet NPCR completeness, timeliness, and quality standards.**

#### ***Activities***

**1.5.1:** Implement procedures to ensure timeliness, quality, and completeness of data in accordance with CDC data quality standards.

**1.5.2:** Inform CDC in a timely manner if barriers to data collection processes or procedures may negatively affect compliance with CDC data quality standards or delay data submission. Work with CDC to resolve and prevent future occurrence.

**1.5.3:** Establish interstate data exchange agreements with other central cancer registries to obtain data on residents who have been diagnosed or treated outside of catchment area and perform data exchanges with them at least twice per year. Quarterly data exchange with geographically bordering central cancer registries is strongly encouraged.

**1.5.4:** CCR's annual data submission adheres to the National and Advanced National Data Quality Standards.

**1.5.5:** Perform linkages with external data sets to improve data completeness and quality.

**1.5.6:** Develop and promote good relationships with reporting facilities.

**1.5.7:** Develop and implement a plan to monitor status of case reporting and completeness.

**1.5.8:** Develop and implement procedures to handle ePath volume effectively.

**1.5.9:** Participate in testing of Registry Plus software, which includes:

1. Installing test versions of Registry Plus software on a desktop computer or test server.
2. Testing the application using protocols provided by the Registry Plus support team.
3. Reporting any issues related to bugs or standards.
4. Installing revised test versions and retesting until all issues have been resolved.

#### ***Performance Measures***

**PM 11:** CCR creates and routinely uses management reports that monitor data reporting, completeness, and quality, attaches templates with the APR submission, and provides a brief explanation of these tools in the narrative.

**PM 12:** Interstate data exchange occurs **at least annually** between CCR and designated states or territories and **quarterly** (if feasible) between CCR and neighboring states.

**PM 13:** CCR's annual data submission adheres to the following data quality criteria for 12- and 24-month data, as measured via the data evaluation report (DER):

1. There are 3% or fewer death-certificate-only cases.
2. There is a 1 per 1,000 or fewer unresolved duplicate rate.
3. The maximum percentage missing for critical data elements are:
  - 2% age.
  - 2% sex.
  - 3% race.
  - 2% county.
4. 99% pass a CDC-prescribed set of standard edits for 12-month data, and 97% pass a CDC-prescribed set of standard edits for 24-month data.

**PM 14:** CCR increases case reporting by at least 2% each year for urologists, dermatologists, and gastroenterologists, as required by law, to demonstrate continuing progress and improvement by the end of the 5-year performance period.

**PM 15:** CCR increases case reporting by at least 2% each year for medical oncologists, radiation oncologists, and hematologists, as required by law, to demonstrate continuing progress and improvement by the end of the 5-year performance period.



## **Standard 1.6: Linkages**

### **Perform linkages to improve data quality, completeness, and accessibility.**

#### ***Activities***

**1.6.1:** Create and employ data linkages as described in the NPCR Program Standards and additional linkages which are necessary for successful registry operations. Linkages include, but are not limited to:

1. State or territory vital statistics (at a minimum, death records) annually.
  2. Indian Health Service administrative records (as appropriate).
  3. Social Security Administration Death Master File annually.
  4. National Death Index annually.
  5. Veterans Administration (if feasible).
- The CCR links with state or territory death files at least once every year and incorporates results on vital status and cause of death into the registry database.
  - The CCR links with the National Death Index at least once every year and incorporates results on vital status and cause of death into the registry database.
  - The CCR links with the state or territory breast and cervical cancer early detection program at least once every year to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.
  - The CCR links with the Indian Health Service (IHS) Administrative Database at least once every five years. However, central cancer registries within IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS at least once every year.

**1.6.2:** Perform linkages that assist in addressing other public health issues as they relate to cancer, including tobacco use, human papillomavirus (HPV) and hepatitis B vaccination, physical activity, and overweight and obesity. Linkages may include behavioral risk factor data such as from the Behavioral Risk Factor Surveillance System (BRFSS), socioeconomic status data, and social determinants of health data, including available data on intersectionality.

- The CCR uses linkages to address gaps identified in data quality and completeness or to improve the utility of the data. Potential sources of information include:
  1. Statewide electronic health files for casefinding and completeness of required data items.
  2. Claims data for casefinding and completeness of required data items.
  3. Census data (or similar) for socio-demographic variables.
  4. Birth records for demographic information.
  5. Department of Motor Vehicle records for demographic information.
  6. Voter registration files for demographic information.
- The CCR should strive to conduct at least one additional linkage per year, inclusive of developing needs such as COVID-19.

#### ***Performance Measures***

**PM 16:** CCR performs linkage with state or territory death files at least **once every year** and incorporates results on vital status and cause of death into the registry database.

**PM 17:** CCR links with the National Death Index at least **once every year** and incorporates results on vital status and cause of death into the registry database.

**PM 18:** CCR links with the state or territory breast and cervical cancer early detection program at least **once every year** to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.

**PM 19:** CCR links with the Indian Health Service (IHS) Administrative Database at least **once every five years**. However, CCRs within IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS at least **once every year**.

## **Standard 1.7: Data Quality Assurance and Education**

**Establish policies, procedures, and processes for data quality assurance that link with education and training to maintain high-quality data.**

### ***Activities***

**1.7.1:** Develop, implement, and maintain an education and training plan for internal staff and reporting facilities with the goal of improving CCR data quality.

**1.7.2:** Conduct internal registry quality control and quality improvement activities by CCR staff.

**1.7.3:** Participate in NPCR-defined national data quality assurance activities including Data Quality Evaluation (DQE) projects, ad hoc data evaluation, audits, and other special data quality control and improvement activities. Complete and submit the Program Evaluation Instrument (PEI) by the due date.

**1.7.4:** Use available training and educational resources and program's ETC to educate staff and reporters.

**1.7.5:** Incorporate findings and results of NPCR Data Evaluation Reports (DER), PEI, and audits into educational and training plans.

**1.7.6:** Conduct routine data quality evaluations showing continuous data quality improvement, for example, lower the percentage of records with unknown values.

### ***Performance Measures***

**PM 11:** CCR creates and routinely uses management reports that monitor data reporting, completeness, and quality, attaches templates with the APR submission, and provides a brief explanation of these tools in the narrative.

**PM 20:** At least once every 5 years, CCR conducts casefinding and re-abstracting audits from a sample of source documents for each hospital-based reporting facility. This is in addition to the CDC-funded and sponsored Data Quality Evaluation (DQE).

**PM 21:** CCR provides at least four online trainings or continuing education opportunities and one in-person workshop (if possible) or training to CCR staff and reporting partners each year.

**PM 22:** CCR meets a percentage completeness each year based on observed-to-expected cases (see **PM 13**).

- **Target:** CCR-submitted 12-month data meets 90% completeness.
- **Target:** CCR-submitted 24-month data meets 95% completeness.

## **Standard 1.8: Data Use and Data Monitoring**

**Use cancer and related program data and disseminate to partners, collaborators, and researchers to expand use of registry data, promote a common understanding of the state or territorial cancer burden, and inform evidence-based decision making.**

### ***Activities***

**1.8.1:** Within 12 months of the end of the diagnosis year with data that are 90% complete, the CCR produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year by Surveillance, Epidemiology, and End Results (SEER) site groups to monitor the top cancer sites within the state or territory.

**1.8.2:** Within 24 months of the end of the diagnosis year with data that are 95% complete, the CCR, in collaboration with local cancer control programs, produces the following electronic reports:

- Reports on age-adjusted incidence and age-adjusted mortality rates for the diagnosis year using SEER site groups and, where applicable, stratifying by age, sex, race, ethnicity, and geographic area.
- Biennial reports providing data on stage and incidence by geographic area, with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors such as tobacco use, overweight and obesity, and human papillomavirus (HPV) infection.

**1.8.3:** The CCR ensures annual use of cancer registry data for public health and surveillance research purposes in **at least five** of the following ways:

1. Comprehensive cancer control.
2. Detailed incidence and mortality by stage and geographic area.
3. Collaboration with cancer screening programs for breast, colorectal, or cervical cancer.
4. Health event investigations.
5. Needs assessment and program planning, such as Community Cancer Profiles.
6. Program evaluation.
7. Epidemiologic studies.
8. Survivorship programs.

### ***Performance Measures***

**PM 23:** CCR submits a success story to CDC **annually** detailing how registry data have been used to affect public health.

**PM 24:** Number of cancer surveillance publications, burden reports, presentations, and data briefs created and disseminated to NPCR and other entities **annually**.

- **Target:** CCR creates and disseminates at least one comprehensive cancer surveillance report that includes age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups stratified by age, sex, race, ethnicity, and/or geographic area.
- **Target:** CCR presents analysis findings to at least two state or territorial groups and one national group each year (NPCR counts as a national group).
- **Target:** CCR collaborates on at least one summary surveillance report outside of the cancer registry, such as environmental health, immunization, nutrition and physical activity, substance abuse (alcohol, marijuana, opioid use), HIV/AIDS, or sexually transmitted infections.
- **Target:** Creates five one-page cancer surveillance data briefs each year.

### **Standard 1.9: Data Submission**

**Submit cancer data to CDC each year in accordance with CDC's standards and requirements.**

#### ***Activities***

**1.9.1:** Submit electronic data files to the NPCR-CSS according to the timeframe and content established by CDC that meet the reporting requirements outlined in the NPCR-CSS Submission Specifications document. Submitted data should meet the criteria for publication in the United States Cancer Statistics (USCS), the National Data Quality Standard, and the Advanced National Data Quality Standard.

- In appropriate data submission years, when the CCR data file meets specified data completeness and quality standards, the CCR data are included in the *Cancer in Five Continents* publication.

**1.9.2:** Participate in all CDC-created and hosted analytic datasets and web-based data query systems as outlined in the annual NPCR-CSS Data Release Policy.

#### ***Performance Measures***

**PM 22:** CCR meets a percent completeness each year based on observed-to-expected cases (see **PM 13**).

- **Target:** CCR-submitted 12-month data meets 90% completeness.
- **Target:** CCR-submitted 24-month data meets 95% completeness.

**PM 25:** Baseline and annual participation in all CDC-created analytic data sets outlined in the NPCR-CSS data release policy.

## **Standard 1.10: Innovation Projects**

**As applicable and available, participate in NPCR-funded innovation projects.**

### ***Activities***

**1.10.1:** Plan, implement, and evaluate innovation projects. Engage cancer coalition leadership and task groups to identify potential project topics.

**1.10.2:** Share promising practices with partners, cancer coalition, collaborators, and cancer program awardees.

**1.10.3:** Participate in CDC sponsored special studies and pilot projects.

### ***Performance Measure***

**PM 26:** Present innovation project findings at one state, territorial, or national conference or meeting **annually** and submit at least one manuscript for publication within the 5-year performance period.

## Strategy 2: Use surveillance systems and population-based surveys to assess cancer burden, examine health disparities, target program efforts, and inform efforts to address social determinants of health (SDOH)

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**Standard 2.1: Share cancer surveillance data with NCCCP, CRCCP, NBCCEDP, and other organizations and agencies to enable implementation of evidence-based interventions.**

**Standard 2.2: Promote and disseminate data to facilitate program planning and evaluation.**

### ***Activities***

**2.1:** Promote use of surveillance data to assess risk factors and health behaviors among populations highly affected by chronic diseases.

**2.2** Produce or participate in the creation of biennial reports of incidence measures appropriate for the cancer and population (rates, counts, proportions) at geographic levels appropriate for the local population (county, city, or statistical health area) for screening-amenable cancers (breast, cervical, colorectal, and lung) diagnosed at a late stage, and cancers associated with overweight and obesity, tobacco, and HPV infection.

**2.3:** Submit the final biennial cancer surveillance report to CDC and disseminate to the state or territory cancer coalition and other partners as appropriate.

### ***Performance Measures***

**PM 27:** CCR creates a target number of cancer surveillance publications, burden reports, presentations, and data briefs and disseminates them to NPCR and other entities **annually**.

- **Target:** CCR creates and disseminates at least one comprehensive cancer surveillance report that includes age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups stratified by age, sex, race, ethnicity, and/or geographic area.
- **Target:** CCR presents analysis findings to at least two state or territorial groups and one national group each year (NPCR counts as a national group).
- **Target:** CCR collaborates on at least one summary surveillance report outside of cancer registry, such as environmental health, immunization, nutrition and physical activity, substance abuse (alcohol, marijuana, opioid use), HIV/AIDS, or sexually transmitted infections.
- **Target:** CCR creates five one-page cancer surveillance data briefs each year.

## Strategy 3: Support program collaboration and external partnerships for cancer control and prevention

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**Standard 3.1: Support collaboration across NPCR, CDC's NBCCEDP, CDC's NCCCP and other chronic disease programs.**

**Standard 3.2: Convene, support, and sustain partnerships and networks necessary to support implementation of cancer program priorities and activities.**

### ***Activities***

**3.1:** The CCR serves on the state, tribal, or territorial cancer coalition to develop and implement data-informed, equity-driven cancer control plans.

**3.2:** The CCR establishes a working relationship with other cancer control programs, including screening programs and tobacco control programs, to assess and implement cancer control activities.

**3.3:** The CCR establishes and regularly convenes an advisory committee to help build consensus, cooperation, and planning for the registry and to enhance chronic disease program coordination and collaboration. Representation should include key organizations and individuals within (such as representatives from all cancer prevention and control components and chronic disease programs) and outside the program (such as hospital cancer registrars, the American Cancer Society, the American College of Surgeons, clinical and laboratory personnel, pathologists, and clinicians). Advisory committees may be structured to meet the needs of the state or territory, such as the comprehensive cancer control program committee structure, an advocacy group, or a focus group.

**3.4:** Use the advisory committee to develop and refine quality improvement initiatives.

**3.5:** Establish and promote greater awareness and use of the cancer registry data.

**3.6:** Collaborate on program planning and identification of populations of focus, based on the jurisdictional cancer control plan.

**3.7:** Share cancer surveillance data with NCCCP, CRCCP, NBCCEDP, and other organizations and agencies identified by the advisory committee to enable implementation of evidence-based interventions for health systems change.

### ***Performance Measures***

**PM 28:** Registry advisory committee meets at least twice per year to discuss CCR data reporting, quality, analysis, use, staffing, special projects, and partnerships.

**PM 29:** Registry advisory committee or cancer coalition develops at least one data quality improvement initiative each year.

## Strategy 5: Conduct program monitoring and evaluation to strengthen program processes and improve equitable outcomes

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Please note: NPCR does not require recipients to implement strategy 4.

**Standard 5.1: Participate in CDC-led program monitoring, evaluation and dissemination activities including periodic data quality audits, PEI surveys, quarterly program updates, and annual success story submissions.**

**Standard 5.2: Develop an evaluation plan according to CDC guidance. This plan should be implemented and reported on annually throughout the 5-year performance period.**

### ***Activities***

**5.1:** Conduct process and outcome evaluation to assess all program activities and use findings to continuously improve registry operations, data quality, and completeness.

**5.2:** Provide an update on annual evaluation progress to CDC in the Annual Progress Report (APR). The update should summarize program monitoring and evaluation findings and describe how findings were used for registry program improvement.

**5.3:** Submit the NPCR Program Evaluation Instrument (PEI) as directed.

**5.4:** Participate in the NPCR Data Quality Evaluation (DQE) as requested.

### ***Performance Measures***

**PM 30:** The CRR adopts the number of quality assurance measures required to meet Advanced National and National Data Quality Standards annually.

- **Target:** CCR implements **at least three** quality assurance measures to meet Advanced National and National Data Quality Standards.